National Cancer Institute

caBIG cancer Biomedical Informatics Grid®

Building a Collaborative Biomedical Network

Question and Answer Session from the caBIG® 2010 Annual Meeting
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The slides that I have are very different than what you've seen from Susan Love and Tom Sellers, although a lot of the themes are the same as you will hear. And so when I was asked to do this panel, they said, "Oh, Deb, just put some thoughts together about how the roles are changing for patients and for consumers and research and medicine and just kind of mix it all up and figure out how this works." So we're going to figure this out together, and I have to blame my slides on cold medication because I'm on that right now. So we'll see where do we go from here. We've heard some really good efforts and different things that are happening. And so what I'm going to do is kind of bring together what's happening in research and what the buzz is and where our system is today and where we're trying to get to. And you've seen some really good examples of some very innovative thoughts on that.

But we hear a lot of promises today on personalized medicine. There are articles all the time about genetic testing, better control, managing, making cancer into a, quote, chronic disease. But the question is really is that all real and is it for real people and is it for everybody because we know how important now biospecimen collections are, but many of those collections, as Susan said are static, they're old technology, but they also have very finite populations in them. And so we don't have a broad spectrum of our entire population in biospecimens. There are multiple risks per person. As our population ages, most people don't just have cancer or they don't just have one cancer. They also may have diabetes or they may have heart conditions, some of that which has been caused by the treatment that they've had. So there are multiple risks that a person has and we hardly ever talk about those.

And so what has to change? And basically the list I have up there means everything. We need to re-think how we're doing research, where the science is taking us, and what that means to the structures and systems that we have in place and how those need to change. And I will—language is important and words are very important, and so I point out a lot of things like that. And Susan brought up the word cure. You know, cure is a really popular term nowadays, but frankly many of us have—and I'm an oldster, I've been doing this for almost 20 years now since my first diagnosis. And so when you say the word cure in an article or a magazine or a scientific journal or on the podium, that has a very different connotation medically—it means a five-year survival rate—than it does to a real person. And until we can get to the person's definition, which means I don't need to worry about this anymore, I think we have to really be careful how that word is used.

Chronic also has real connotations in many ways, not to mention federal, funding, legal, all of those kinds of things. And while I applaud the enthusiasm that the oncology community has in being able to make cancer less of a life-threatening illness in some cases, certainly not all, we're not really at that point. And one of my comebacks to that is that I don't know too many diabetes patients that are really happy with their chronic illness. So I think we need to remember that while we are making good advances, we're not there yet and the angle really is to get rid of this stinking disease.

So with that said, I'm going to make a point about hype. And you'll see a few letters of the alphabet. I actually took a few out because, again, this is cold medication coming through. But hype, we hype a lot of things. And a lot of it is from enthusiasm with really good people and scientists that are doing their work, but they are so focused on their one scientific point that they're trying to find, that they get over zealous sometimes and make statements about something that really isn't as significant on an overall scale as what they've led us to believe. So we have a couple quotes here about something that happened a couple years ago with Herceptin, Traz—I can never say it right—Trastuzumab in adjuvant chemotherapy. That was the big deal is that now we've shown that for women with HER2+ breast cancer, Herceptin actually helps them too. And there was someone who is—both of these people are wonderful, dedicated people who actually talked about this, that we now have a cure for breast cancer.

And the problem with that is that there's still in 2009 almost 200,000 people getting breast cancer and unfortunately about 41,000 who die every year. And I think we have to be really careful about what we say and that we're giving the public the wrong message. And so there's a lot of mistrust that can actually be formed by that. So even though I'm talking primarily to a technology audience, we all need to be participating in making the advances that we have real for people and we really need good results. We have a lot of good news. There are more survivors. There are more discoveries every day. It also creates more expectations in an environment where there are shrinking costs and more regulations. But the danger of not doing this well is real. It's palpable to real people. And it means that if we have false negative or positive tests, for instance, biomarker tests that are out or genetic tests that are out, that actually affects millions of people potentially. If we can't validate the science that's going on, that causes problems as well. And the bottom line is it wastes a lot of time. So we have to do things differently and we've heard how that can happen.

Okay, we make things hard through our regulations sometimes. And HIPAA is our friend. Unfortunately, a lot of patients cannot get access to their own records because of the way HIPAA has been implemented within institutions. There are many barriers that have been set up for that. There are multiple permissions that we need, both in patient care as well as in different research. A lot of doctors steer people away from research because we don't like to admit that we don't have the answer. Well, there isn't the answer as we're finding out for different groups of people. And not having genetic tests or markers in every clinical trial or within patient care now means that we have fewer options or answers available for smaller groups of people that we can find out about.

So here's my first letter. And I bring this up because this is one of the elephants in the room that hardly anybody ever talks about, but I see it as a major barrier to having us work more closely together and getting involved. And I'll explain that in a minute because the cold medicine says I have to take a drink. Okay, many of you are from institutions that pride themselves on excellence. We have grant programs that are set up with excellence in their name, and that's an excellent thing to strive for. The problem with that is that it also brings up kind of the dark side of research and can actually impede the progress that we're trying to make because of elitism. And the language that is used by people creates elitism, and that's just the beginning. There are major egos involved, and we all know who they are because they tell us all the time. There is an—and I think I spelled this wrong, I apologize—empiricism meaning empire building. And I know some of you have been maybe perhaps victims as well as beneficiaries of that. But what all of that does is it erodes trust. And the trust is exactly what we need, not only with the public but within the scientific community because of all the people that have to work together. So if we're going to focus on E words, I'd like us to focus on the last two: experience and effectiveness because that means more to people. It's where we actually make progress and get things done. And the fact is that can happen everywhere. It doesn't have to happen just in excellent institutions.

So having said that, I thought I'd look at this from different viewpoints. So if I'm looking at this with my friends here in the audience, the view from caBIG®-ers, data is what we talk about and data is what we focus on and what are we going to do with that data, where is it, how are we going to use it, who gets to, all of that kind of stuff. Okay? Right? Okay. Here's the view from other people, including patients and people. Data's important but it's only one of many tools that are out there that can help identify options for people going through a major illness or a disease. The whole reason that we're here is because people get sick or injured. And so the data is a tool; it is not the universe. And I think it's really important to remember that because it's easy to get carried away and to just focus on that piece of it. It's only going to be useful if it's usable to me and whoever I decide I want to give it to. That could be my doctor or, frankly, in today's world the ten doctors that I have to work with because everybody's a specialist. It could be family members. It could not be family members. It could be all sorts of different people. It could be the world. If you think of how Facebook is set up, for example, and who you give certain information to and who you don't, that's how we need to be developing the systems that we're looking at today with the way Facebook and Google and whatever's going to be next, that's what we need to be planning for now. And, of course, I want that information protected from misuse from any direction.

So that may sound like a tall order, but frankly that's what people are looking for. And part of that at least is do-able and it's certainly something we have to keep in mind. So when I talk about it's not about the data, what is it about? Well, it's really about new answers to old problems that are faced in medical research and patient care. And our goal really should be, if we can continue to remember this part rather than focusing on the data, is to improve the results of care, therapy, prevention, whatever it is by anybody who can improve that so that the data is available to anybody wherever they are and where the data is and not for us to just document the same

old way we do things today. And a lot of times in the discussions I hear within caBIG®, we're talking about documenting the way things are done today. Now we have to start somewhere and that's fine.

I'm also going to put in a plea here for SMEs. Is there anybody in the audience who's a SME and do you know who you are? SMEs are subject matter experts, okay? Because I don't see very many hands, I see this as a major problem. SMEs are not peripheral to this enterprise. SMEs are not only integral, but they are the reason why we are developing the tools and services within caBIG®. So I need everybody in this room to stop talking past each other and to stop avoiding SMEs and getting them involved in caBIG® and let's really focus on what their needs are because they are on the frontline with patients. And that's why we're developing caBIG® tools.

Traditionally we've had a major divide between research and medicine. And as you've heard today, we're changing that concept so that basically we've got patients and people who are being taken care of both by research and by medicine and care. And we have some things that are moving in that direction that are helping us. In the "-omics" world, no matter what kind of -omics you're talking about and I've heard some pretty funny ones lately, the great news is none of the -omics have enough patients because where we're going with this is subdividing the patient populations so that there are smaller and smaller groups of people. Well, guess what? One institution is not going to be able to find all of the people that they need for that subgroup which means they have to start working more together which means we can start knocking down some of the barriers that we've built up to coordination and collaboration.

We need additional scientific fields for research and care. So the question is how do we connect them better. People and patients are partners; they're not subjects anymore. Now we have to change the regulations and that takes years. But, frankly, that impetus has been happening and many of us have been challenging that kind of language for a long time because we need to change the mindset of how we do research and how we partner together. People, as you can see from both of the other presentations, will contribute to research and they want to benefit from the knowledge, both for themselves and for their family members. And that knowledge needs to come back into the healthcare system. So it's very much a loop nowadays, and yet our structure isn't set up that way so we have to change that.

I have at least seven different health records that I know of right now in all of my different doctor offices, and I know some of you have many more than that. So the question is how are we going to integrate all of the information so a person can get their hands on all of their health information, not just pieces of it in certain places. And I'm just going to say one other word that I didn't use is consumer, even though that's in our vernacular now, because I truly don't know anyone who wants to consume cancer. They don't even really want to consume healthcare. I mean, the people that consume healthcare are those of us that know we're patients. But, frankly, I'm looking at an entire room of people who will be using healthcare some time in your life if you haven't already. So we're all in this boat together. Now if we want to use that word because we can't come up with a better one, fine. I just had to make that point.

Okay, so one more alphabet word, and I'm going to try to go through this quickly. But we've all heard SOA, right? You know what that means? SOA really is so important to us. And from a patient standpoint it's very important too. I do have to say I'm so happy now that we have a model and an acronym that we can apply these thoughts to because many of us have been trying to get that approach taken from the beginning of the caBIG® project. I think Charlie Mead and Ken have said you make easy things easy to do. Well, in using my S terminology here, I put it in systematic sand trap seeks standard solutions. And you can probably put simple in there too. We really do need to study the operational situations, the process that people are using and how can we impact and improve that along with the technology solutions that we're providing to them. And we've done a lot of good things. There's a lot of progress that's been made through caBIG® in a relatively short amount of time. But now it's time to clean up our own house as well to make the products as easy to use as they can be for people that don't have technology backgrounds. And that's a major challenge that we have to get past. So the SOA concept actually makes a lot of sense to patients, and it should speed up delivery of care. But, again, instead of the hype, I want us to be able to show the results first and then we can sell it. So we have a lot of work which means we've got to talk a lot together and make things happen.

They asked me to say what Patient Advocates In Research do, and you've heard some different ideas here. Many people are patient advocates and do different things, but those of us that are involved, for instance, in caBIG® and in cancer research always challenge and ask questions. That's part of our job so don't get mad at us for doing that. And we're always doing it to focus on the end results of what is this going to mean to a person, how are we actually going to make a difference, are we just doing busy work here or are we actually making progress. We discuss information flows and so there's now a patient BAM along with other BAMs that are being integrated together. So that's one example.

We do help combat systemic problems, and we can address these from different directions and we can engage more of the advocacy community in this. And we've done some of these things but there are others that we really need to be doing as well. We're definitely involved in the clinical trial process and trying to make it better, sharing information. We're trying to help with some of the regulations and the harmonization that needs to take place. For caBIG® we always push for practical successes. So the products that are out there are good ones to begin with and the services. The fact is we need the integration and the interoperability is critical. If it's not there, people are not going to use it. And usability is an issue that really needs to be addressed full force in caBIG®. There are also other fields that you hear about like patient-reported outcomes, etc. that we know are going to impact the tools that are being built within caBIG®. And so those are things that we bring to mind.

So I'd like for us to, in a wrap up, to focus on this kind of formula rather than just focusing on the data. We have to move the data through the process as quickly as possible for people so that we get to results. And that means that we have to form new ways of connections and working together. And IT, meaning IT and information technology, can actually make that happen. And I think that we can work together

because, as patient advocates, we can help connect the dots in ways that you can't necessarily connect them through the system. So that's one of the thoughts I'd like to leave you with and thank you very much.

Speakers:

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